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ABSTRACT

This guide to whole life planning for people with disabilities describes whole life planning as a person-centered way of assisting people with disabilities to plan for their future. Whole life planning relies on the involvement of a small group of committed people who are willing to act as advocates and resources to the focal person. The manual includes examples from a statewide project in Massachusetts that assist young adults in making the transition from school to adult life. Chapters present the process divided into the following steps: (1) organizing the planning process, which involves deciding who will participate in the planning, when and where it will take place, and the role of the facilitator; (2) developing a personal profile, including the places, people, and activities in a person's life; (3) building a vision, which involves highlighting major, recurring themes from the personal profile that point the way to a desirable future for the individual and developing vision statements; (4) developing action plans, which involve specific and immediate actions to implement goals; and (5) supporting networks and plans, which include follow-up meetings to evaluate progress. Appendices include a social network interview guide and sample worksheets. (CR)

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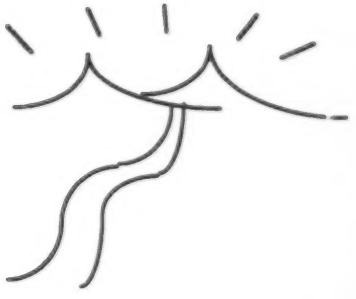
Whole Life Planning

A Guide for Organizers and Facilitators



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A Guide for Organizers and Facilitators

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School	Community Partner
Brookline Public Schools	Brookline Adult and Continuing Education
Boston Public Schools	Boston Private Industry Council
Middleboro Public Schools	Community Partnerships, Inc.
Holyoke Public Schools	FOR Community Services, Inc.
Southwick-Tolland Regional School District	Aditus, Inc.
Waltham Public Schools	G.W.A.R.C., Inc.

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Whole Life Planning

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Whole Life Planning

A Guide for Organizers and Facilitators

Some form of planning is involved in most of our important life decisions. Where should I go on vacation this year? Should I change jobs? Events may not always turn out as planned, but we do not neglect the planning process because of that. We make new plans.

Plans made in one area of our lives affect other areas. Where we live influences the kind of work available to us, and vice versa. Making one big purchase may mean postponing another purchase, and so on.

Many times we turn to others for advice, information, and guidance in making our plans; people we know and trust. These may include people with whom our lives are closely linked, so we plan for *our* vacation or where *we* will live. Our relationships are partly the result of our plans, and are partly the resources we use to develop and implement new plans.

To *implement* our plans, we sometimes seek the services of paid professionals -- counselors, doctors, travel agents, tax accountants, and so forth. And we receive a good deal of support on an informal, unpaid basis as well, from friends, family members, co-workers, and neighbors. To *develop* our plans, we tend to rely more on help from people in this informal network -- people who care about us without being paid to, who know us well, and whom we trust.

People with disabilities may need particular assistance with life planning because:

- The life alternatives available have traditionally been limited to a narrow range,
- Expectations for life goals and achievements have tended to be low, and
- Many individuals need assistance with articulating their vision for the future and with the process of making decisions.

People with disabilities get support from both formal and informal sources to develop and implement their plans as do other people. But often the support they receive is weighted heavily towards the formal side. And paid professionals have more often been the primary resource to help individuals *develop* as well as to *implement* their plans. As a result,

- People with disabilities risk becoming increasingly dependent on professionals and decreasingly connected to informal support resources in their community, and

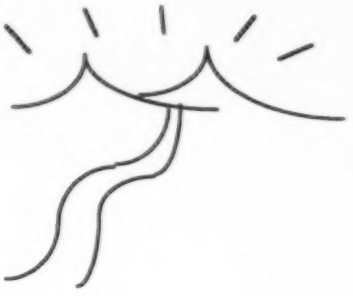
- Professionals often have a vested interest in what plans a person makes -- some are easier for them to help implement, some are hard to find funding for, and so forth -- and these considerations may dominate the planning process.

Whole life planning is a way of assisting people with disabilities to plan for their future. It is a process for defining those quality of life outcomes desired by the individual in work, social relationships, living, and leisure; and for developing a plan to reach towards that vision. Whole life planning helps clarify and organize personal interests and choices. Whole life planning also encourages the participation of family and friends in establishing and achieving personal goals.

Through whole life planning, we can achieve a balance between formal and informal support resources and help people define and implement a personal vision for their life that is broader than the traditional or easily available options. This guide is an overview of the whole life planning approach.

> Stan and his family live in a small rural community. Because Stan wanted to move to a living situation more on his own after high school, his family was planning to apply for placement for Stan in a group home in a neighboring city. But through Stan's whole life planning process, it became clear that Stan's ties to his home community were important, and that moving would be disruptive to his life. The planning team talked about alternatives closer to home, and began researching the option of adding an apartment with a separate entrance as an addition to the family home.

What is Whole Life Planning?



Several alternative approaches to planning have been developed in recent years, referred to as personal futures planning, life-style planning, or outcome-based planning (Beeman & Ducharme, 1988; Bolles, 1989; Mount & Zwernik, 1988; O'Brien, 1987; Steere, Wood, Pancsofar, & Butterworth, 1990). These approaches share several features:

- A focus on the preferences, talents, and dreams of an individual rather than needs or limitations;
- An emphasis on the contributions and participation of the person with a disability and significant others from their life in the planning process, usually in a group meeting format;
- Defining an unrestricted vision of the lifestyle the individual would like to have and the goals needed to achieve that vision;
- Identifying the supports and/or resources an individual needs to reach his or her goals;
- Organizing resources and supports that are as local, informal, and generic or "non-professional" as possible to implement plans.

This guide incorporates these features into a person-centered planning approach. It relies on the involvement of a small group of committed people who are willing to act as advocates and resources to the focal person. It emphasizes involvement of family, friends, and community members.

Whole life planning is *not* a meeting. There can be whole life planning without meetings and meetings without whole life planning. It may involve one or more gatherings of small and large groups of people, but the core of whole life planning involves forging new relationships between people and their communities. In the example above, it was not until the third gathering that it became clear to Stan and his friends and family that a group home would not meet his priorities and a new vision began to form. At this point, the group called on community resources like the town engineer to help in designing an "in-law apartment" in accordance with town zoning requirements, and began to implement Stan's vision.

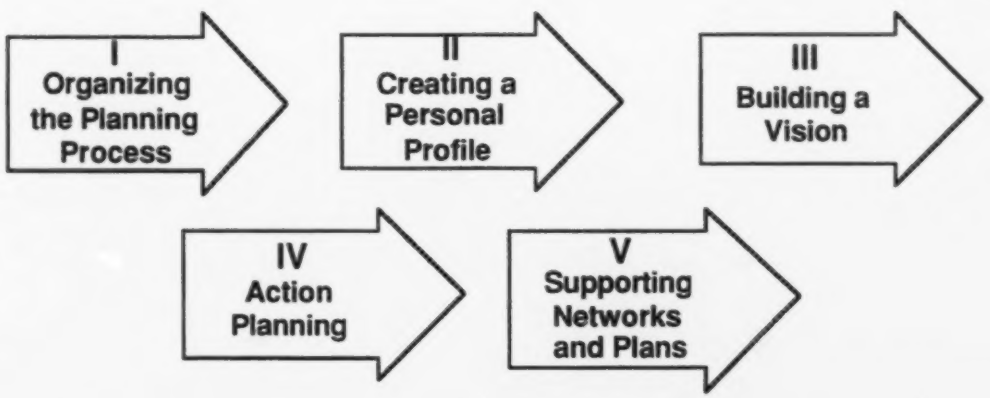
How Does Whole Life Planning Relate to IEPs, ISPs, and IWRPs?

Many people are familiar with the planning processes agencies use in serving individuals with disabilities. Whole life planning is separate from developing an agency service plan, such as an Individual Education Plan (IEP), Individual Service Plan (ISP), Individual Written Rehabilitation Plan (IWRP), or any variation on these processes. The whole life plan is the *person's* plan, not a school's or an agency's plan. The individual does not *participate* in whole life planning, he or she *controls* it.

A whole life plan may incorporate "non-human-service" approaches, such as joining a club or taking an adult education class. Or, it may use creative, non-traditional solutions to service needs, such as paying a neighbor to serve as job developer or funding transportation to work through a Social Security PASS Plan. Agency services and traditional funding sources will also be needed by many individuals with significant disabilities, and these are incorporated as part of a whole life plan. The whole life plan provides guidance for the development of agency planning documents and the goals and visions of the whole life plan are reflected in them, as paid services are sought or molded to support each personal vision.

> *"People with disabilities have IEPs, IWRPs, ISPs and IHPs. Me, I just p."*
> -- Ernest Pancsofar

There is no one recipe for whole life planning. This manual explains some of the options and examples of planning processes we have found successful in several demonstration projects. Most of the examples are from a statewide project in Massachusetts to assist young adults to make the transition from school to adult life.



The sequence of steps is designed to help a planning process begin with a clear vision for the future, and, once that has been clearly defined, progress to setting specific action steps. We encourage you to follow the steps in order as presented to ensure that plans are based on the individual's vision for the future and not the convenience of available resources. Effective brainstorming relies on an unrestricted view of the alternatives! Within each step, the manual presents examples of variations that can be made.

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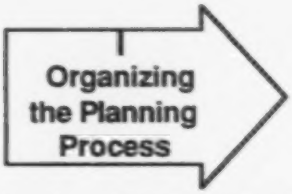


Organizing whole life planning involves developing a partnership with an individual, helping recruit participation from others, and identifying a planning structure and format that works for everyone involved. This organizational phase takes time and requires one or more conversations with the focal person and possibly his or her family. Most whole life planning will involve one or more additional group meetings, with the organizer serving as the facilitator or recruiting another individual to facilitate these meetings.

It is the personal dynamic and commitment of the participants that define a successful process. The organizer sets the tone for that dynamic. An individual with a disability can serve as his or her own organizer, or a family member, other relative, friend, roommate, teacher, case manager, peer advocate, counselor, or any other individual in a position to offer assistance can serve as the organizer. You, the reader, as an individual interested in the well-being of someone with a disability, would make a great organizer.

Who, When, and Where

A central task of the organizer is to help the individual decide who will participate in the planning and when and where it will take place. This may involve visiting with the person and, if he or she agrees, with his or her family at their home to describe the process. This may also be a good time to begin developing the personal profile and identifying particular concerns and priorities. These priorities can serve as agenda items for the meeting. The individual's preferences should dictate each element of the planning format.

Who. People involved should be chosen by the person -- people whom the individual likes and trusts most and people who know the person best. The proposed agenda can also be considered in developing the invitation list.

Some individuals know right away whom they want to invite. Other individuals need the organizer or a close friend or relative to help with the selection process. One way to assist is to review a typical day with the individual and identify the people the individual comes in contact with and ask about those people. Another method is to ask about the people in various roles in their lives:

- Family members and relatives,

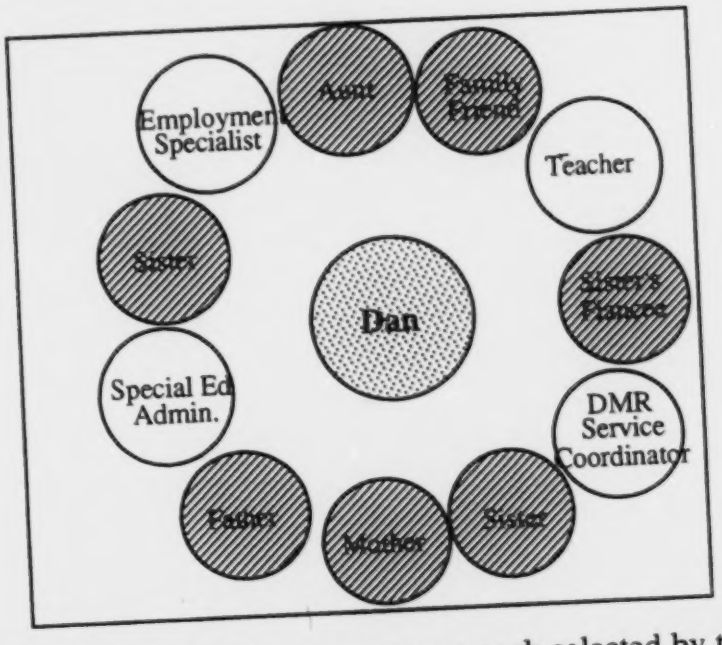
- Friends and acquaintances,
- Co-workers or classmates,
- Neighbors,
- Professionals or business people, such as teachers, doctors, shopkeepers,
- Members of any social, religious, or civic organizations the individual is connected with.

A useful tool for mapping the significant people in an individual's life is the Social Network Interview. A guide for conducting a social network interview and sample form are included with this guide as an Appendix.

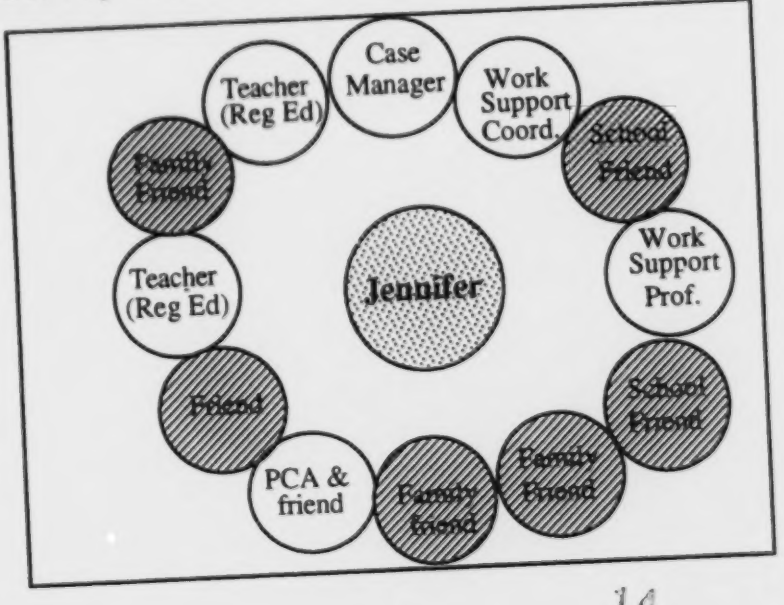
Selecting a planning group is not just a matter of "rounding up the usual suspects." Effective whole life planning relies on a group that is chosen by the individual and primarily represents family, friends, and community resources. Each guest list reflects the style of the focal person. One person may prefer a small meeting while another enjoys a gala event.

> Some individuals may know people in the community but not by name. John liked to talk with two women who worked at a neighborhood photocopy shop and wanted to invite them to a planning meeting, but didn't know their names. John went to the shop with Shirley, the organizer, and Jim pointed out the individuals. Introductions were made, and John invited the women to his meeting.

Disability program staff and professionals may be invited for their knowledge, expertise, and connections. They should not be selected to represent a particular agency. And it is extremely important that professionals not dominate the meeting by their sheer numbers. Two examples are shown on the following page.



Dan and Jennifer's planning groups were each selected by the focal person and, in Dan's case, with help from his family. Both groups emphasize family and friends, and both represent very personal choices that at times may be difficult to make. Jennifer invited two regular education teachers who co-teach a senior seminar she is enrolled in, but did not invite the special education staff who work with her. Jennifer also did not invite her mother, although she allowed the meeting to be videotaped so her mother could watch it later. Dan's mother invited May, a family friend who is a primary source of support to her.



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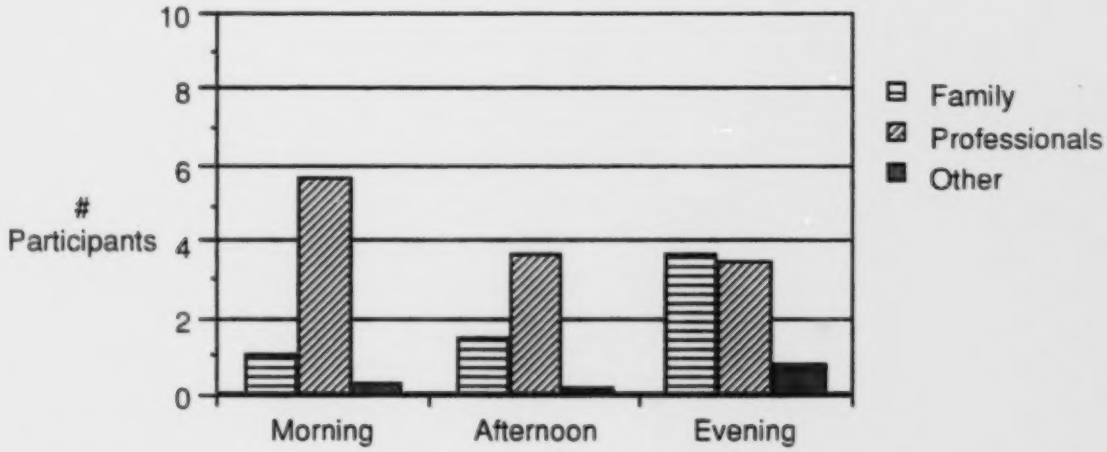
When. The day of the week and time of day are important considerations in planning, and an organizer needs to be willing to schedule meetings at non-typical times. Evenings or weekends are often best for a person and their family.

> Bill held his planning meeting on a Sunday afternoon at home. It was important to him that his parents, Uncle Jack, Aunt Janice, grandparents and teacher attend his planning meeting. Sunday afternoon happened to be the best time for everyone to meet. They made his planning meeting a family get together, complete with Sunday dinner.

The time of day a meeting is held will affect who attends. The chart below reflects our experiences on participation in whole life planning meetings in a statewide demonstration project. Professionals dominated morning meetings, but evening meetings showed more of a balance among family members, other informal support people, and professionals.



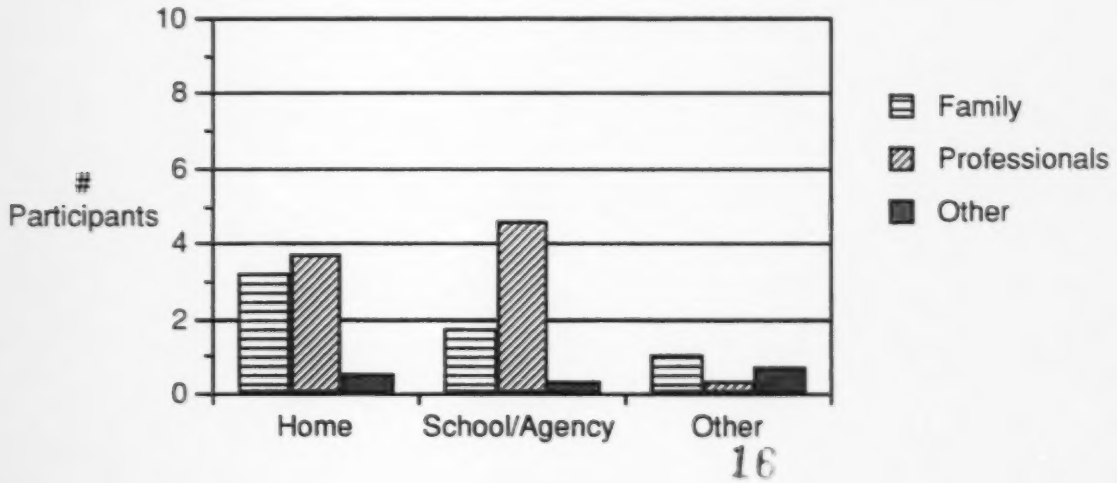
Where. Planning can take place in any location comfortable for the individual. Many people choose their home. Home is a familiar setting, and acting as the "host" can be an important aspect of control over the process for the individual. Homes may also contain photographs and other articles that convey information about a person's interests and relationships. Other planning locations can include a library, church, or other community meeting room, or a restaurant. Some gatherings have been outdoors, in the context of a barbecue or picnic.

> To help in organizing a meeting at his home, Jim made a grocery list, went food shopping with his organizer, and prepared the refreshments. This established a clear sense of Jim's "ownership" of the planning process which was evident throughout the meeting.

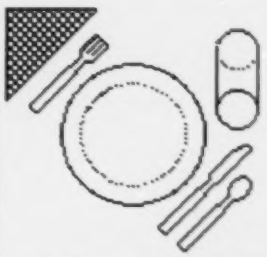
Try to avoid service settings. It will be hard to make the meeting clearly different from other meetings the focal person and their family attend there. It will also be difficult to ensure a good balance of attendees. If there is no alternative, make the planning meeting as different as possible from the formal meetings held there.

> Mike's meeting took place during the early Fall. The participants gathered on the deck outside of his house, and his family acted as host and offered drinks to participants as they arrived. As it got darker, the session moved inside to the living room.

In our project, where meetings were held influenced the balance between informal support resources and professionals, as the graph below indicates.



The comfort level and style of a meeting is also established by the way people are greeted as they arrive, the availability of food and drink, and the way the meeting is set up (e.g. formally around a table or casually sitting around the living room). Meetings around snacks or a potluck supper provide a relaxed atmosphere, and also give participants an opportunity to contribute.



Food and drink add to the positive atmosphere of a gathering. Carmen held her initial group meeting in the kitchen of her sister's apartment at dinner time. About halfway through the meeting the participants broke for lasagna and salad. During dinner Carmen's parents talked about their fears about Carmen going to work in a way they were not comfortable doing in the meeting itself. Participants returned to the table energized, and with new insights from dinnertime conversation.

Meetings and Alternative Formats

As the examples show, many times whole life planning is conducted as one or more group meetings. Meetings can be especially valuable for several reasons.

- Different people with different perspectives are brought together.
- Groups can brainstorm, with one person's idea stimulating new ideas that people would not have thought of otherwise.
- Commitments in a group meeting are made in a publicly recognized way.
- Participating in a planning group helps members to appreciate and support the vision and goals of the individual.

We recommend a group meeting format whenever there is not a strong reason not to use a group. But sometimes there is such a reason. Some people dislike being the center of attention at a group meeting, and sometimes not all those invited may be able to agree on the same time and place. Several alternatives can be considered.

- Individual meetings between the person and each member of the planning group, with the organizer assisting the person to put the pieces together into an overall plan.
- A series of interviews of key people by the organizer, who then reports back and meets with the individual.

- Two or more smaller meetings may be held.
- A planning session that includes only the individual and the organizer.
- A prior videotaped interview with individual shown to the planning group as the basis for a discussion which is then reported back to the individual.

> Rob distrusts most people and so did not want to have a group meet to talk about his life and his goals. He chose instead to develop his profile and personal vision with the organizer during a quiet one-on-one walk in his favorite place, a local bird sanctuary.

Another alternative is to split the planning into two parts and use a different format for each part. Perhaps the most common is to use one of the above formats for the personal profile phase (discussed below) followed by a group meeting to carry out the subsequent phases.

> The facilitator for Lisa's whole life plan developed the profile section of the plan by meeting separately with Lisa, her mother, and her teacher. This preliminary profile information was then presented at a group meeting, where additional information was added. The group then helped Lisa develop her vision for the future and brainstormed ways to help make it happen.

The group may even be split into two smaller groups with one group developing the vision and another developing the action plan.

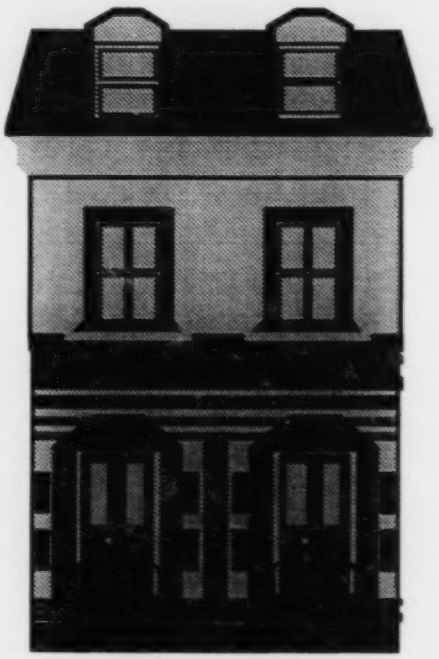
> Nick met with his friends to brainstorm ways to be included in regular education classes, clubs and after school activities. Over pizza, they discussed activities that they could do together. One of Nick's friends kept notes on their ideas. Later, these ideas were presented to Nick's parents and key adults in Nick's life to help develop implementation strategies.

A meeting does not have to be *called* a "meeting" or a "whole life planning session." That can make it sound stuffy and formal. Those invited can be asked to "come over to my house for a get together for pizza and to talk with me about some of my plans," or whatever seems most natural for the individual.

Invitations

Participants can receive either written or telephone invitations. How an invitation is communicated is important to both the focal person and those invited. Invitations should always be from the person and worded in a personal way. For example, John's teacher helped him make invitations for a coffee and

dessert get together using the classroom computer. John then handed invitations to the people he wanted to invite.



YOU ARE INVITED

FOR DESSERT & COFFEE

WHERE: JOHN'S HOUSE

WHEN: JUNE 27, 1993

6:30 - 8:30 PM

HELP ME

PLAN MY FUTURE!

HOPE YOU CAN COME!

The checklist on page 14 provides a reference for some of the major things that make planning successful.

Whole Life Planning Checklist for Organizers

- ❑ Meet with the individual (and family or guardian if applicable) to
  - ✔ Review purpose of planning process
  - ✔ Plan for the individual's participation
  - ✔ Decide on group meeting or alternative format
  - ✔ Highlight priority life areas or concerns

- ❑ Map significant others with the individual and select participants
  - ✔ Who can help the individual to articulate a vision?
  - ✔ Who has access to needed information or resources?
  - ✔ Who can support the action plans developed?
  - ✔ Have all significant relationships been considered? (e.g. family, friends, people who have a significant connection to the family, co-workers)?
  - ✔ Is the size of the group comfortable? Would the individual be comfortable discussing the proposed topic with each person?

- ❑ Assign roles for the planning process
  - ✔ Identify or recruit a facilitator
  - ✔ Other participants can bring refreshments, arrange the location, help with invitations, take minutes, or take responsibility for distributing minutes following the meeting
  - ✔ Is there a potential co-facilitator who may sustain the planning team for the long term?

- ❑ Arrange a location and time
  - ✔ Comfortable for all attending
  - ✔ Allows full participation of family and friends
  - ✔ Consider either the individual's home, friend's home, or a restaurant or church meeting room

- ❑ Assist the individual to send invitations
  - ✔ Make it personal
  - ✔ By phone, in writing, or in-person
  - ✔ Will written invitations be purchased or hand-made, mailed or hand-delivered?
  - ✔ What is the RSVP procedure?

- ❑ Help the facilitator(s) prepare an agenda and supplies for the meeting
  - ✔ Will a flip chart, paper and markers be used?
  - ✔ Will any background information be distributed?

The Role of the Facilitator

Facilitating planning meetings requires care and thought. An effective facilitator:

- Has good listening skills.
- Is able to actively involve all of the participants.
- Facilitates creative thinking by providing a clear vision of an inclusive community and flexible supports.
- Maintains the group's focus on positive visions rather than potential problems.
- Remains neutral regarding options and strategies.

The facilitator's role is to lead the group through the process by:

- Explaining the agenda and purpose.
- Facilitating participation of the focal person.
- Assuring full participation by family members, friends, and community members.
- Managing conflict or disagreement among participants.
- Setting and maintaining ground rules for group interaction.
- Asking open ended questions to generate a complete record of key life experiences, preferences, and choices.
- Recording all comments (unless another individual serves as recorder).
- Ensuring the meeting begins and ends on schedule.

Some facilitators have training or experience in this type of planning activity, but attitude and approach are more important than experience. Most important is that the individual is comfortable with who is selected. Perhaps second in importance is the ability to think creatively and positively. When someone in a disability service role -- a teacher, case manager, or other program staff person -- is the most logical individual to facilitate the meeting, it is important to make sure the individual is able to fully step outside of their usual employment role for this purpose. An individual in the community with expertise in group process and/or career planning for people without disabilities, or a family member or family friend can also be asked to serve as facilitator.

Sometimes an individual can be identified to begin as a co-facilitator or recorder who then can become comfortable with facilitating future planning sessions on his or her own.

General Strategies for a Facilitator

- ❑ Provide an agenda and brief summary of the purpose of each meeting, perhaps as a written handout or on chart paper at the beginning of the meeting.
- ❑ Make sure everyone is introduced.
- ❑ Review the ground rules.
- ❑ Ask open ended questions.
- ❑ Ask follow-up questions that prompt people to expand on comments and fill in details.
- ❑ Make each person aware that their presence and contribution is important.
- ❑ Reinforce *all* comments, no matter how small or repetitive, by
  - ☞ Summarizing or paraphrasing each comment
  - ☞ Writing down each comment, even repetitive ones, on chart paper.
- ❑ Encourage family participation by asking them first.
- ❑ If someone is hogging the floor,
  - ☞ Change to an area they are not expert in and return to that topic later
  - ☞ Take turns around the room, asking one person at a time to contribute an idea to the topic being worked on.
- ❑ If its comfortable for you and the participants, use chart paper and colored markers to record the meeting. Tape the chart paper to the walls so that as many sheets as possible are visible. (Comments and conversations are not linear -- they move around pretty freely). Or identify a recorder or co-facilitator who can take notes.
- ❑ Stick to the agenda and agreed-upon time limits.
- ❑ Celebrate the contributions other people make to the process by
  - ☞ Recognizing contributions in the meeting.
  - ☞ Assisting the individual to send thank you notes.
- ❑ Make sure people take time to enjoy the refreshments and talk casually. Never underestimate the role of food and drink in a gathering.
- ❑ Use humor frequently. Humor relaxes people and also releases their creativity. People need to feel comfortable before they can brainstorm ideas creatively.

Good Things to Say

- ✔ *Tell us more about that...*
- ✔ *Why do you think that is?*
- ✔ *What did you like best about that? Why?*
- ✔ *What was it about that you didn't like?*
- ✔ *Can you give us an example?*
- ✔ *That's a great comment...idea...insight...*

Starting and Ending Meetings

The way a planning process or meeting begins establishes the style and tone for participants' interaction. Be prepared to provide a written (printed or on flip chart paper) or verbal agenda, establish some ground rules for participants, and clearly define the purpose of the meeting so that participants know why they are there.

Sample Purpose Statements

- ☞ *To help the individual to better define a personal vision of what he or she wants to be and do (either in general or in relation to a specific issue or life transition)*
- ☞ *To identify and recruit resources, and supports to help him or her reach that vision. These resources may include the school, family, friends, workplaces, community or social groups, or other relationships.*
- ☞ *To help the individual develop new relationships, strengthen existing relationships, and play a positive role in community life.*

The agenda for a meeting may follow the structure outlined in the following sections: Personal Profile, Developing a Vision, and Action Planning. Alternatively you might combine the steps and organize the process by life area. Formats for both of these approaches are provided as an Appendix.

Ground Rules

- ☞ *Agree on an ending time for the meeting.*
- ☞ *Length of time commitment expected beyond the initial meeting.*
- ☞ *Focus is on defining a desirable life style. We will be careful not to consider barriers or problems while we are defining the individual's preferences and dreams.*
- ☞ *We may disagree about many things during this meeting, and no one should hold back those comments. We will note disagreements, but we will not try to resolve them here. We will instead focus on the things we want to do.*
- ☞ *Everyone's input is equally important.*

Different groups feel differently about this, but in general 1 1/2 to 2 hours is a reasonable outside limit for a meeting. After that people begin to get tired and lose focus. Whole life planning has been done in all day sessions, but we don't recommend that approach. Plan clear beginning and ending times for meetings, and make sure everyone knows what they are. If you need to run over to finish something, make sure that you ask the group's permission. It's better to end early so that people have time to hang around and talk afterwards.

Minutes

Before the meeting a specific person should be chosen to record and summarize the meeting and distribute the summary to each of the participants. The facilitator *may* have all or some of that role. If he or she is recording the meeting on chart paper, then someone else may be responsible for summarizing the information. Or someone else may agree to serve as recorder and take all of the notes.

Make sure that minutes get distributed to participants as soon after the meeting as possible (at least within a week of the meeting). There are no specific rules for how minutes are structured. They can be formal or informal, handwritten or typed.

Forward a copy of the minutes to any people not in attendance who will be responsible for developing agency service plans for the individual.

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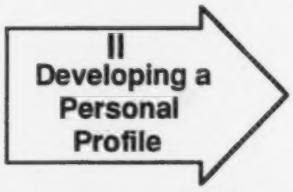

The personal profile is a comprehensive inventory of the places, people, and activities in a person's life. The purpose is to gain a deeper understanding of the individual's preferences, dislikes, and choices. Information from one part of a person's life may provide important clues to the vision and standards for other parts of their life. For example, preferences and choices at home may provide insight to the kind of work situation a person would enjoy.

Two Approaches to the Profile

The profile can be developed with a planning group, or it can be developed ahead of time with the focal person and possibly his or her family as part of the organizing phase. Developing it with the group may provide a richer experience and prepare participants to be more open to a range of possible plans. However, it will also take significantly more time, and it may be difficult to ensure that both the focal person and participants fully contribute.

Developing the profile ahead of time ensures that the focal person has control over the content, and will be a more efficient use of the larger group's time. The beginning of the meeting can be used to share this information with the larger group, and to update or expand on the information. The focal person may also use this opportunity to prepare a personal statement using words, pictures, or videotape for the group. The group can then step relatively quickly into action planning. Allow the focal person to decide which of these two approaches best suits them.

> Sally was concerned that her personal priorities differed somewhat from those of her family and, she felt, from those of some of her teachers. She developed a personal profile with the facilitator and prepared a brief statement about her goals and priorities for her life. When the planning group convened, she began the meeting with her statement of priorities, followed by a review of the profile information.

Organizing the Profile

It helps to organize the profile by major segments of the person's life to make sure that you cover everything. Once the conversation gets rolling, your job is to keep it going and tease out the details. The headings below can serve as an organizing outline.

Review of a person's history and their relationships may help to provide context for the rest of the discussion. These areas can be considered optional, subject to time limitations and the preferences of the person. Most of the time in this phase should be spent reviewing the major areas of their life (home, work, school, leisure and recreation), and discussing in detail likes and dislikes about each activity.

As the profile is developed, ask why the individual likes or dislikes the activities mentioned. Asking questions helps reveal hidden interests and preferences. The questions below are only suggestions.

> Susan stated that math was her favorite class. However, when the facilitator asked her to expand on why she liked it, it turned out that math was her favorite class because her best friend was in the class, not because she truly liked math.

In general, it helps to record comments on large sheets of paper (e.g. flip chart paper) so that everyone can see it. Likes and dislikes can be noted in separate columns or in different colors (e.g. red for dislikes, green for likes). We prefer to use a separate sheet of paper for each life area, plus an additional sheet for summary or general information. A sample layout is provided as an Appendix.

Be careful not to get too hung up on the order in which you cover the information. If you have several sheets of paper taped up, you can bounce between the areas and a summary of preferences and dislikes while people talk. It's a good idea to start with a topic area that family and friends can provide most of the information for (e.g. don't start with school).

Background and personal history (optional). Ask a central person or the focal person to give the group some history and perspective by reviewing significant milestones or events in the persons life. This is very personal, and you should ask someone ahead of time if they would be able to do this. A history is particularly useful if it is important that planning participants better understand the context of a person and their desires. This may be particularly true for someone who has a reputation for behavior that challenges others, for example, or someone who has lived in an institution.

Personal History: Things to Ask

- ✔ *What are the key milestones in your life?*
- ✔ *What major moves or transitions have you made?*
- ✔ *How has your health been? How is it now?*
- ✔ *What have been the most important positive experiences in your life?*
- ✔ *What have been the most difficult experiences?*

Relationships (optional). Share the map of relationships and significant others developed while organizing the planning process. Ask participants for additional members or input:

- ☞ Family (Immediate and extended)
- ☞ Friends (Personal friends, Family friends, School, work, ...)
- ☞ Community resources (Church, recreation or social groups, ...)
- ☞ Professional supports and services

Relationships: Things to Ask:

- ✔ *With whom do you spend the most time with on a daily and weekly basis?*
- ✔ *Are there other important people in your life that you spend time with only occasionally?*
- ✔ *Who are your friends and allies?*
- ✔ *Who will act as an advocate for your interests?*
- ✔ *Who do you go to for help or advice?*

Life areas. The discussion should spend a substantial amount of time on each major area of the focal person's life. It usually helps to address one life area at a time, although these discussions are rarely completely linear and the facilitator should be prepared to move around as appropriate. If you are using flip chart paper it is also helpful to reserve a sheet for general comments and observations that cross over life areas. As a point is made, or a pattern becomes clear, then it can be highlighted there.

One way of ensuring a comprehensive discussion is to begin with an inventory of all of the activities a person engages in within that life area. This can be summarized if the profile is completed prior to the group meeting. Once the inventory is complete, then likes and dislikes can be catalogued for each activity. Be careful to explore the *reasons* for preferences. Often why a person like or dislikes something is more important than the activity itself. A facilitator should ask "why" frequently.

Life Areas: Things to Ask

Home:

- ✔ *What chores or responsibilities do you have?*
- ✔ *What do you do for fun?*
- ✔ *What hobbies or special interests do you have?*
- ✔ *What do you do when there is nothing else to do?*
- ✔ *What do you to with your family? With friends?*
- ✔ *What are your favorite things to do at home? Why?*
- ✔ *What are your least favorite things to do at home? Why?*
- ✔ *What is your best time of day?*

School:

- ✔ *What is a typical daily schedule?*
- ✔ *What other less frequent activities are you involved with?*
- ✔ *What are your favorite classes? Why? Are there things you don't like about those classes?*
- ✔ *What are your least favorite classes? Why? Are there things you like about those classes?*
- ✔ *What clubs or extracurricular activities are you involved with? What do you like about each? What don't you like about each?*
- ✔ *How do you get to school and back home?*

Work:

- ✔ *What jobs have you held? For pay? As a volunteer? School responsibilities or jobs? Job training experiences?*
- ✔ *Tell me about each of those jobs. What did you do there?*
- ✔ *What do/did you like about each of those jobs? Why?*
- ✔ *What do/did you dislike about each of those jobs? Why?*

Recreation and Leisure:

- ✔ *What clubs or sports do you participate in?*
- ✔ *How do you get there and back?*
- ✔ *How do you spend vacations?*
- ✔ *What do you like to do most in your free time? Why? What about those activities is fun? What don't you like about those activities?*
- ✔ *What don't you like to do in your free time? Why? What about those activities don't you like? Are there parts of those activities that are fun?*

On the next page is a sample of notes in the area of work from Carmen's planning session.

Work		
Job History	Likes	Dislikes
School Library •slash cards •Stamp Cards •Straighten shelves	-slashing cards -fun to use pen -sit at desk	doing same job all day
Town Hall Cafeteria	-water sprayer -moving fast -wearing uniform -food (lunch)	-not being able to sit down -standing all day
School Cafeteria	-co-workers -walking to work (not too far) -having drinks at work -hours working (10-1) -sitting down during down time	
Middle School Office •File cards & letters	-fun to play cards -work with boyfriend	-working alone

◆

Building a vision requires merging and synthesizing the information in the profile into a coherent set of comments and standards that define those things that are most important to the person. This phase is the core of whole life planning. The facilitator's role is to help highlight those major, recurring themes from the personal profile that point the way to a desirable future for the individual. Examples of themes might be that a person enjoys being around a lot of people, likes to be outdoors, or likes a lot of autonomy in structuring her daily routine.

Building a Vision: Things to Ask

- ✔ *What would your ideal typical day look like?*
- ✔ *What is your vision of an ideal future...*
  - *Where will you live? What will it be like?*
  - *Where will you work? What will it be like?*
  - *How will you spend your free time?*
  - *Who will you spend time with? Regularly? Occasionally?*
- ✔ *What places or community environments will you use?*
- ✔ *What new things do you want to learn? What role should continuing education play?*

In some successful planning sessions invited participants who were not able to attend submitted their vision in writing. One such contribution is excerpted below.

Dear Jennifer,

My dream for you is that you live in a big Victorian house in the Brookline area. The house has five bedrooms and big kitchen, living room, and dining room where you can have lots of friends over for dinner. The house is totally accessible by wheelchair. You live there with a few other roommates or maybe you even own the house co-operatively with them. It's a lot of responsibility to own a home but it also feels really good. There is room in the house for aides to stay so that there is always someone there to help you to do whatever you need to do.

There is plenty of room in the back for parking a wheelchair van so your aides can bring you and your friends shopping and to movies and for walks and dinner in Chinatown when the weather is nice.

The best part is that you have a little factory where you package a small but wonderful line of organic, biodegradable laundry and household soap that is made for you by a private-label manufacturer. The business sells that soap locally and nationally. You appear on the Oprah Winfrey show. You invite me to be on the show with you and I am nervous but accept.

Love,

Seth

Vision statements can be developed as narratives, as in the case of Seth's contribution to Jennifer's plan, or they can be detailed lists of critical features of a life area such as in Jim's vision of work life, below. Both of these vision statements establish clear boundaries that define whether or not you have made it. They also are not too restrictive. Many jobs or workplaces could meet Jim's standards.

Vision for Work: Jim

People
- opportunities to make friends
- work in a group or team

Work
- keep busy and active
- work with machines
- have a clear finished product

Appreciation
- be recognized for work
- good pay

Structure
- clear responsibilities
- tasks that are fairly easy to learn

Schedule
- no early hours

Reality and Visions

A frequent concern for participants is that a vision or dream is "not realistic" or "not possible". It is important for the facilitator to not let these views block the formation of a broad and exciting vision.

Providing each participant with a few minutes to quietly imagine the best future for the focal person, area by area, may help to free people from mental blocks.

> Katie loved to sing and act and dreamed of being an actress. Her vision was supported by her whole life planning group. She enrolled in voice lessons through Adult Education and joined a theater group that offered acting lessons. Katie is learning new skills and making friends with "connections" in theater arts.

The whole life planning group looks for creative options which allow the individual to explore aspects of the vision which match his/her skills, abilities, and preferences.

> Ken loves to talk about emergency services and vehicles (police, fire, ambulance), but doesn't have the skills needed to be a police officer, firefighter, or EMT. A connection was made with the local fire department and department of public works. Ken assists with the maintenance and care of the vehicles involved in emergency services.

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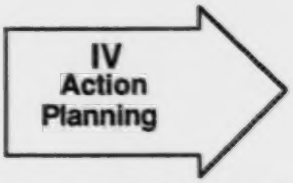


Visions have little meaning unless something happens to implement them. Whole life planning can be a powerful catalyst for change in an individual's life. Change can't happen, however, unless planning results in *specific* and *immediate* actions. It is important that action steps are agreed to and put in writing, with an individual assigned to implement them. It may be helpful to designate a time frame or set a follow up meeting to discuss progress.

> *Being on the wire is living... anything else is just waiting.*
> -- Karl Wallenda

Action steps can include:

- Steps the focal person can take,
- Steps others helping with the planning can take,
- Steps others in the community can be asked to take, and
- Steps schools or service provider agencies can be asked to take.

Action Planning: Things to Ask

- ✔ *What would it take to accomplish ...?*
- ✔ *What are the next steps towards these goals?*
- ✔ *Who is the most logical person to take each step?*
- ✔ *Who else do we need to get involved? Who are the experts? Who knows them?*
- ✔ *What can each person commit to?*

The summary below, from Ben's planning session in the area of school, follows a format that is particularly effective at generating action plans.

School		
Preferences	Vision	Action Plans
likes being with friends	more friends at high school	arrange to be in regular home room get involved in school activities - Judy
likes baseball	wants to be involved in baseball at high school	obtain information regarding baseball team - Gail Mc.

likes American history	take American history course	enroll in Mrs. T's American history course in fall - Judy
likes art	would like art class	explore options for attending art class with 2 or 3 classmates - Susan
loved carpentry in middle school	take carpentry course	explore ways to obtain in-school carpentry training - Pete investigate carpentry training programs - Pat explore possibility of employment as carpenter's helper - Pat

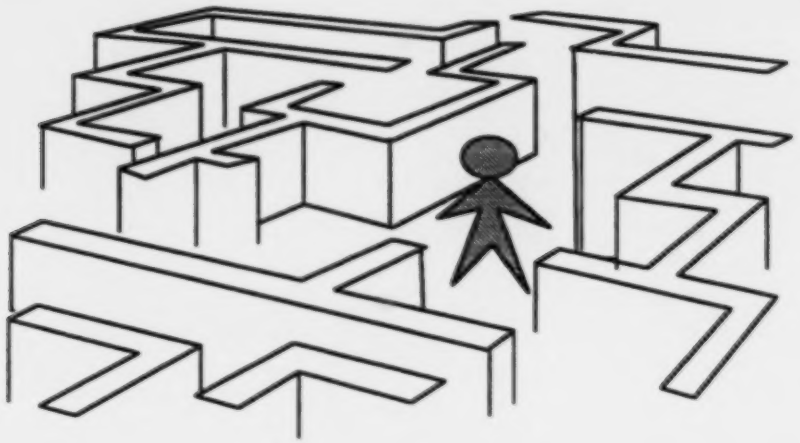
The Scope of Planning

Some parts of an action plan can be implemented directly by planning participants.

> At Ben's meeting he revealed an interest in American history that his teacher, Judy, had not been aware of before. She helped him enroll in a regular education American history course the following semester.

Other parts of a plan, like Stan's plan to construct an addition to the family home, require a complex series of steps.

Often, all the steps needed to reach a vision cannot be foreseen. In the case above, no carpentry training program could be found that met Ben's needs. Gail then began working with Ben's family to identify possible connections to individuals in the building trades. Other times, actions involve large, complicated interactions with systems or bureaucracies that can seem impossible to understand. Dealing with bureaucracies can be overwhelming without support and assistance from others. Use teamwork!



In our project, many students had the same dreams as their high school peers: Dating, having money, getting a car, going to college, and similar goals.

How many life areas are included in a plan, and how far into the future planning extends, are highly individualized. Some adolescents or adults just beginning to think about the future might begin with fairly immediate planning needs. Dan's strongest wish was to publish a story in the town newspaper. John wanted help getting into a karate class and to begin dating girls. The notion of planning his "whole life" was too formidable and abstract. As planning evolves, longer term issues may arise. John's mother was very surprised to find, during his second meeting, that John had thought about what would happen when she died.

Strategizing

As the facilitator assists the planning team to develop strategies, the following suggestions may be helpful:

- Use the network resources of each and every member. Ask the kind of questions that get members thinking "Who do I know who can help?"
- Consider adding new members to the planning group who have expertise or connections in a desired area, or asking them for help with a specific task.
- Break action plans down into smaller, more manageable steps. Ask, "How can we begin to reach this goal?"
- Whenever possible, consider generic resources before those that are more specialized. Generic services are usually easier to access, available to everyone, and involve less "red tape". They also represent the way most people get what they need.

- Network with organizations and groups that can help "fill in the gaps," such as Parent Advisory Committees, Local Advisory Boards, etc.

- Let others accept responsibility. No one person can be responsible for follow-up on all action plans or do everything alone. Don't try to wear too many hats!

It is important to keep in mind that not everyone involved in planning needs to assume responsibility for action steps. Contributions come in many forms.

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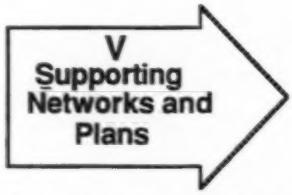

Based on the action plans they have developed, the planning group may decide to continue to meet periodically to monitor and coordinate progress and solve problems, or may choose to disband and implement plans individually. Either way, a clear plan for ongoing support and follow-up is needed. This may include both the informal supports from family, friends, and community and formal supports, including professional services and changes in school curricula.

The role of the facilitator may now begin to evolve into that of a coordinator, keeping in touch with members and monitoring progress; or another person (family member, friend, or the individual him/herself) may want to assume these responsibilities.

Follow-up meetings can provide updates to members of the planning group and provide opportunities to develop new strategies and ideas. Each time the group meets, notes from the previous meeting are reviewed. The group shares information on "what was done" and "how things went". New action plans or goals can then be developed if needed. New members may be invited to join the planning group as goals evolve in new directions or new connections are made.

> Stan and his family were interested in building an addition to their house for him to live in after he graduated from high school. Stan's family and friends met regularly as they explored creative options to achieve his dream. Building plans were developed; grants and donations were sought for building materials; and funding for personal care assistants were investigated. As the group investigated options, they contacted a diverse group of professionals and organizations for assistance which included architects, service groups, legislative aides, the zoning board, independent living groups, etc.

Some whole life planning groups may choose to meet on a regular basis to provide ongoing support or work toward a long term goal. These groups evolve into a "circle of support".

Some whole life planning groups break into subcommittees to work on specific projects, and arrange to meet again to discuss progress. In other cases, the person may decide to reconvene group when the need for a new plan arises.

Beth was unexpectedly laid off from her job as a housekeeper. Her whole life planning team quickly reconvened to discuss future employment prospects. As Beth discussed her last job, it became clear to her that she didn't like some aspects of it, particularly the social isolation. Through community connections, she got a job as a porter in a retirement home. She delivers meals to the residents and works in the kitchen as part of a team. Beth enjoys her new position and knows that she can count on her whole life planning group for support.

Planning may be reactivated (a) based on the timetable suggested by the plan itself -- for example, if a plan is to assist an individual to obtain a job that meets particular requirements, the group might reconvene once the job begins; (b) in response to a specific life event, as in Beth's case above; or (c) a group may schedule a meeting shortly before an important agency service planning meeting, to prepare for that meeting and assist the individual to identify what he or she would like from the service.

The results of planning set the stage for new activities and new relationships. As the person gains new experiences, their goals and dreams may change. The planning group can help the individual to meet new goals. As the person builds new relationships, the "circle of support" can be expanded to include these new friends. Planning and relationship building are interrelated. The process is ongoing, with goals, dreams, and circumstances continually changing. Over time, informal resources become stronger as relationships are built and the group realizes the power of the planning process.

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Final Words
(or....who is this for, anyway?)

If one advances confidently in the direction of his dreams, And endeavors to live that life which he has imagined, he will meet with a success unexpected.... If you have built castles in the air, your work need not be lost. That is where they should be. Now put the foundations under them.

-- Henry David Thoreau

Some people find it difficult to separate whole life planning from agency service planning. To make matters worse, some agencies have begun to use or mandate a process that seems similar or uses the same language. As we have noted, the goals and visions of the whole life plan should provide guidance for the development of agency-driven planning documents. However, the whole life plan is broader in scope and not confined by an agency's mission and resources. Goals of a whole life plan may be met through traditional service delivery or through creative, non-traditional means. At times the goals may be overtly at odds with agency resources or priorities.

No process required and controlled by an agency can truly be a whole life planning process. No plan recorded on an agency form and filed in an office file cabinet can truly be a person's plan.

At its heart, whole life planning is an interactive process, not a product. No official document is produced, and the results do not legally bind anyone to doing anything. The success of the process rests on the flexibility and creativity of the people in an individual's life who care about him or her, including family, friends, community relationships, teachers, and other professionals.

Because it is such an individual process, the structure and flow vary considerably from person to person. Whole life planning calls upon organizers and facilitators to be flexible, creative, and sensitive to the participants and the focal person. Most of all, whole life planning is a lot of fun.

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Appendices

Social Network Interview Guide

Sample Chartpaper Layouts: Format A

Sample Chartpaper Layouts: Format B

Social Network Interview Guide

Instructions

Column A: Ask the questions below and enter each name mentioned, showing the individual what you're writing.

Column B: List each person's relationship to the interviewee:
R= Relative: Family member or other kin including "in-laws";
S= Staff: Paid human service worker, including respite or family care provider if paid:
F= Friend: Anyone not R or S, including acquaintances, co-workers, etc.
***= Friend is a special education student or a disability service consumer (if known)

Column C: Enter support types based on the indented questions. Use any available "props" or information about the individual to help the individual think of examples and situations that apply to each question.
S=Socialization/Companionship **T**=Tangible/Material Help
G=Guidance/Advice **E**=Emotional Support/Intimacy

Column D: **X**= At least one type of support is experienced as reciprocal.

Column E: For relationships coded **F** (friends) ask how or where the interviewee met the individual.

Where do you live? Who lives there with you? Anyone else?

Which of these people do you like to talk with or do things with? (**S**)

If you need help with anything at home, like finding something, fixing something, or doing laundry (agree on some situations), who would you ask for help? Anyone else? (**T**)

Is there anyone you do things for at home to help them out? Anyone else? (**X**)

What do you do during the week? Who do you usually see there? Anyone else?

Which people do you like to talk to or do things with? Anyone else? (**S**)
Who do you like to have lunch or breaks with? Anyone else? (**S**)

If you needed help at work or school, (ask for examples: lifting something heavy, finding something, etc.) who would you ask ? Anything else you need help with? Who helps? (**T**)

Is there someone who sometimes asks you to help them with anything at work or school? Anyone else? (**X**)

Have you ever forgotten your lunch or needed to borrow some extra money at school or work? (Discuss a situation that could apply.) Who could you ask? Anyone else? (**T**)

Is there anyone who might borrow money from you? (**X**)

What do you do after school or work? Who do you do that with? Anyone else?

What do you do on weekends? Who do you do that with? Anyone else?

Is there anyone else you go out and do things with? Anyone else you get together with for fun or to talk with?
Last week did you:

	How many times ?	Who were you with?
Visit someone at their home?	**H**=_____	"
Shop at a store or mall?	**S**=_____	"
Go to a restaurant, coffee shop or bar?	**R**=_____	"
Go to the movies or a concert?	**M**=_____	"
Go to a sports event?	**S**=_____	"
Go to a health facility like the YMCA?	**H**=_____	"
Go to a party or dance?	**P**=_____	"

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Which of these people (review names from last 4 questions) do you like to talk with or do things with? (**S**)

If you need help with things, like where to find something, or to help carry something (agree on a few examples), which of these people would you ask for help? (**T**)
Would they ever ask you for help? (**X**)

Which people do you know in your neighborhood?

Is there anyone who works in any stores or business offices whom you have gotten to know?

Who do you sometimes visit with at their house? Anyone else?

Which of these people (review names from last 3 questions) do you like to talk with or visit with? (**S**)
Have you invited anyone to visit you? (**X**)

Who do you get cards from, like on your birthday, or sends you letters? Anyone else?

Do you like to hear from them? (**S**) Who do you write to? (**X**)

Who do you talk with on the telephone? Anyone else?

Do you like to talk with them? (**S**) Who do you call? (**X**)

Are there any organizations or groups in the community that you are a member of?

- Religious Congregation? _____
- Groups or clubs or teams? _____
- Any other organizations that have meetings or events? _____

Who do you talk with or like in (each organization)? Anyone else? (**S**)

(Review the whole list of names). Is there anyone else important to you who should be on the list?

What is something you have that you really like (or ask about something the person has with them: jewelry, watch, etc.)? If you needed someone to take care of it for you and keep it safe, which of all these people would you ask? Anyone else? (**E**)

Do you ever need to borrow something, like a pen, a book, paper, aspirin? Who do you ask? Anyone else? (**T**)

Is there anyone who has borrowed something like that from you? Anyone else? (**X**)

Do you have a boyfriend or girlfriend? Who is that? (**E**)

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Is there anyone who comes to you for advice when they have to make a decision? Anyone else? (**X**)

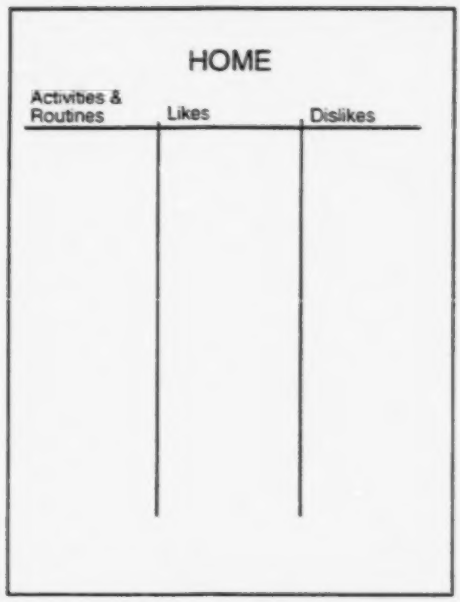
Social Network Interview Guide

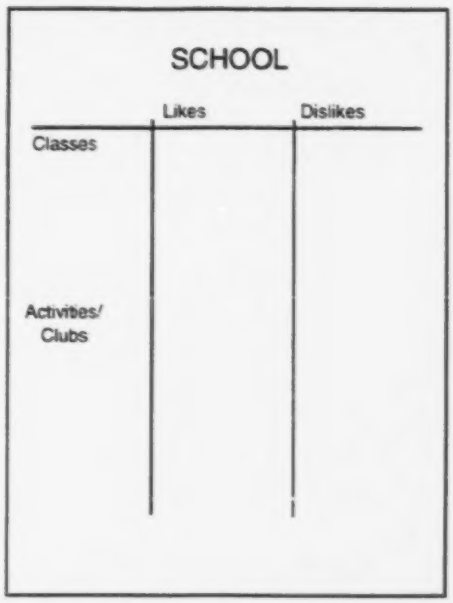
Name_____

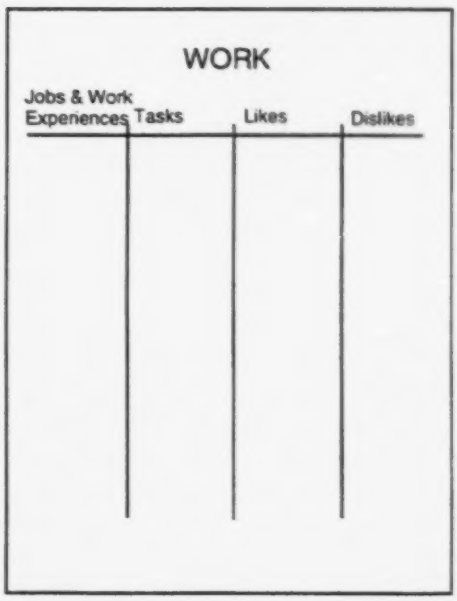
Interviewed by_____ Date_____

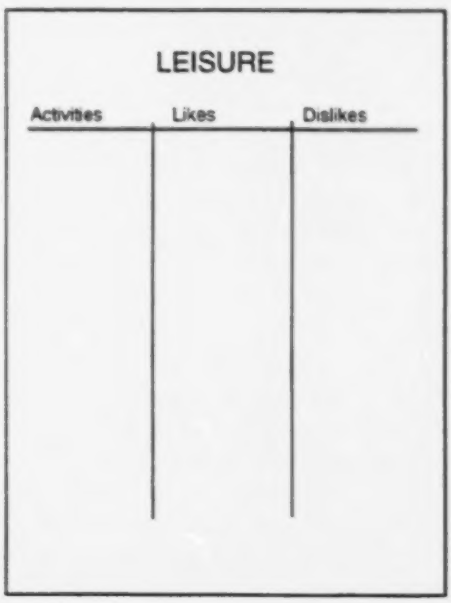
Name	Relationship (R, S, F, *)	Support Types (S, T, G, E)	Reciprocal? (X)	How Met Friends?

Sample Chartpaper Layouts: Format A









Sample Chartpaper Layouts: Format A
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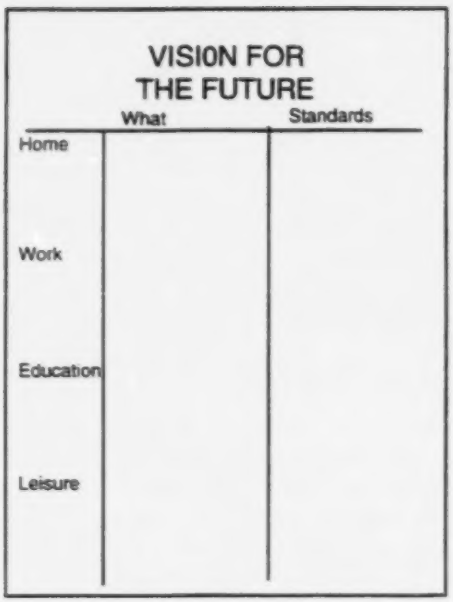
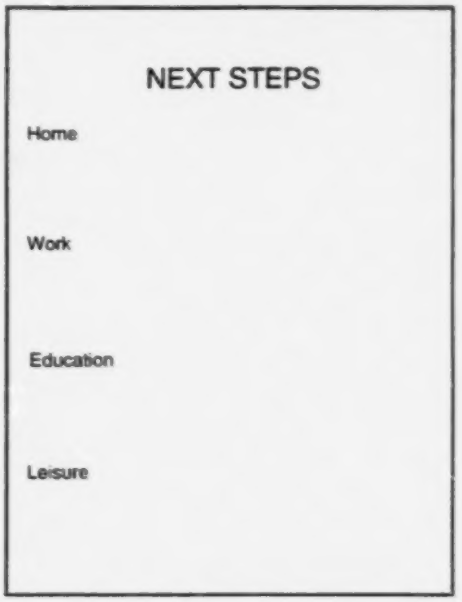
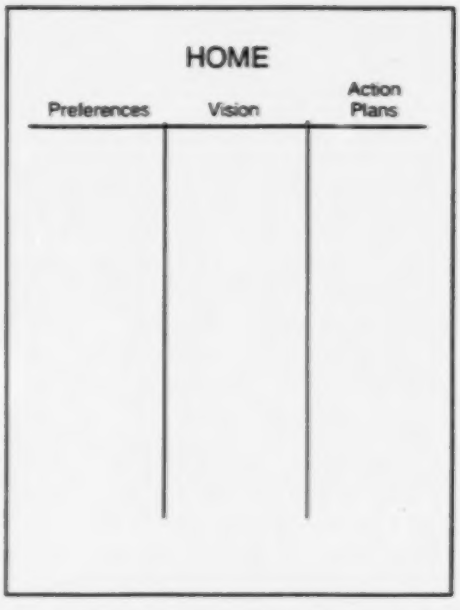
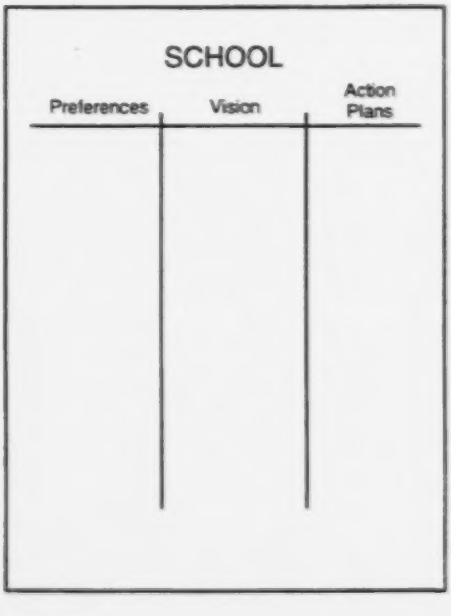
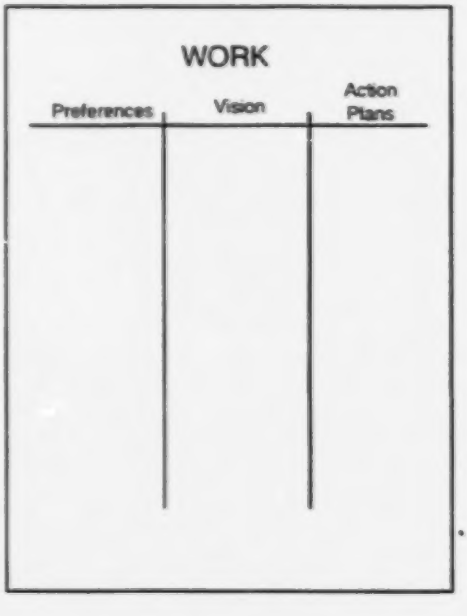




Sample Chartpaper Layouts: Format B







Sample Chartpaper Layouts: Format B
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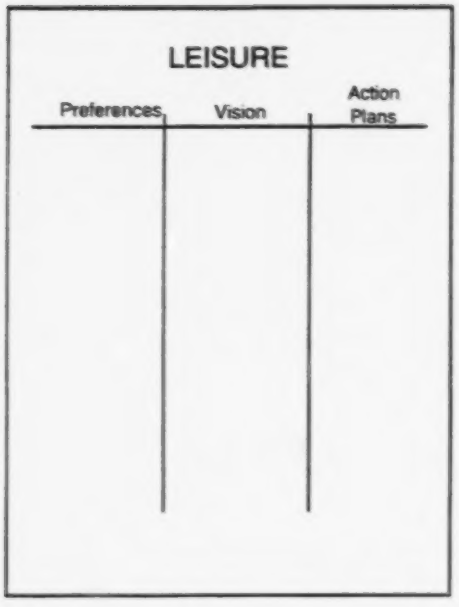

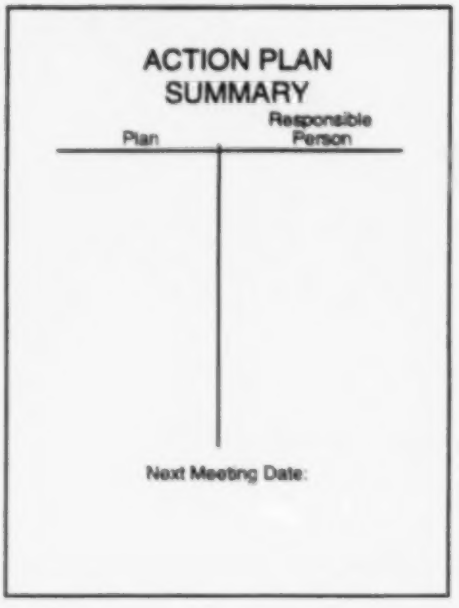

Social Network Interview Guide

Instructions

Column A: Ask the questions below and enter each name mentioned, showing the individual what you're writing.

Column B: List each person's relationship to the interviewee:
R= Relative: Family member or other kin including "in-laws";
S= Staff: Paid human service worker, including respite or family care provider if paid:
F= Friend: Anyone not R or S, including acquaintances, co-workers, etc.
***= Friend is a special education student or a disability service consumer (if known)

Column C: Enter support types based on the indented questions. Use any available "props" or information about the individual to help the individual think of examples and situations that apply to each question.
S=Socialization/Companionship **T**=Tangible/Material Help
G=Guidance/Advice **E**=Emotional Support/Intimacy

Column D: **X**= At least one type of support is experienced as reciprocal.

Column E: For relationships coded **F** (friends) ask how or where the interviewee met the individual.

Where do you live? Who lives there with you? Anyone else?

Which of these people do you like to talk with or do things with? (**S**)

If you need help with anything at home, like finding something, fixing something, or doing laundry (agree on some situations), who would you ask for help? Anyone else? (**T**)

Is there anyone you do things for at home to help them out? Anyone else? (**X**)

What do you do during the week? Who do you usually see there? Anyone else?

Which people do you like to talk to or do things with? Anyone else? (**S**)
Who do you like to have lunch or breaks with? Anyone else? (**S**)

If you needed help at work or school, (ask for examples: lifting something heavy, finding something, etc.) who would you ask ? Anything else you need help with? Who helps? (**T**)

Is there someone who sometimes asks you to help them with anything at work or school? Anyone else? (**X**)

Have you ever forgotten your lunch or needed to borrow some extra money at school or work? (Discuss a situation that could apply.) Who could you ask? Anyone else? (**T**)

Is there anyone who might borrow money from you? (**X**)

What do you do after school or work? Who do you do that with? Anyone else?

What do you do on weekends? Who do you do that with? Anyone else?

Is there anyone else you go out and do things with? Anyone else you get together with for fun or to talk with?
Last week did you:

	How many times ?	Who were you with?
Visit someone at their home?	H=_____	"
Shop at a store or mall?	S=_____	"
Go to a restaurant, coffee shop or bar?	R=_____	"
Go to the movies or a concert?	M=_____	"
Go to a sports event?	S=_____	"
Go to a health facility like the YMCA?	H=_____	"
Go to a party or dance?	P=_____	"

Which of these people (review names from last 4 questions) do you like to talk with or do things with? (**S**)

If you need help with things, like where to find something, or to help carry something (agree on a few examples), which of these people would you ask for help? (**T**)
Would they ever ask you for help? (**X**)

Which people do you know in your neighborhood?

Is there anyone who works in any stores or business offices whom you have gotten to know?

Who do you sometimes visit with at their house? Anyone else?

Which of these people (review names from last 3 questions) do you like to talk with or visit with? (**S**)
Have you invited anyone to visit you? (**X**)

Who do you get cards from, like on your birthday, or sends you letters? Anyone else?

Do you like to hear from them? (**S**) Who do you write to? (**X**)

Who do you talk with on the telephone? Anyone else?

Do you like to talk with them? (**S**) Who do you call? (**X**)

Are there any organizations or groups in the community that you are a member of?

- Religious Congregation? _____
- Groups or clubs or teams? _____
- Any other organizations that have meetings or events? _____

Who do you talk with or like in (each organization)? Anyone else? (**S**)

(Review the whole list of names). Is there anyone else important to you who should be on the list?

What is something you have that you really like (or ask about something the person has with them: jewelry, watch, etc.)? If you needed someone to take care of it for you and keep it safe, which of all these people would you ask? Anyone else? (**E**)

Do you ever need to borrow something, like a pen, a book, paper, aspirin? Who do you ask? Anyone else? (**T**)

Is there anyone who has borrowed something like that from you? Anyone else? (**X**)

Do you have a boyfriend or girlfriend? Who is that? (**E**)

Do you ever have something personal and private to tell somebody? Or a secret? Or something bothers you that you need to talk with somebody about? Who do you talk to? Anyone else? (**E**)

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Social Network Interview Guide

Name_____

Interviewed by_____ Date_____

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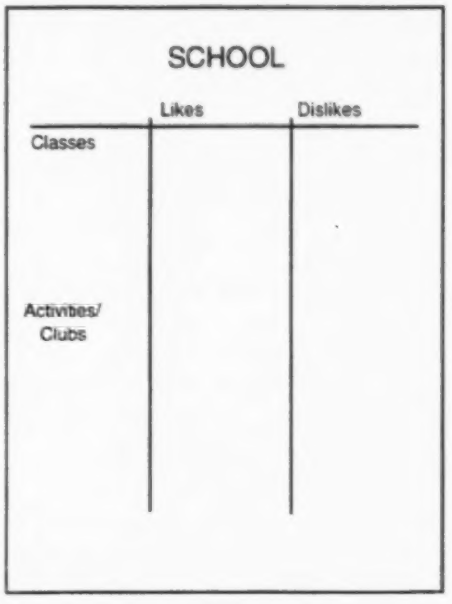

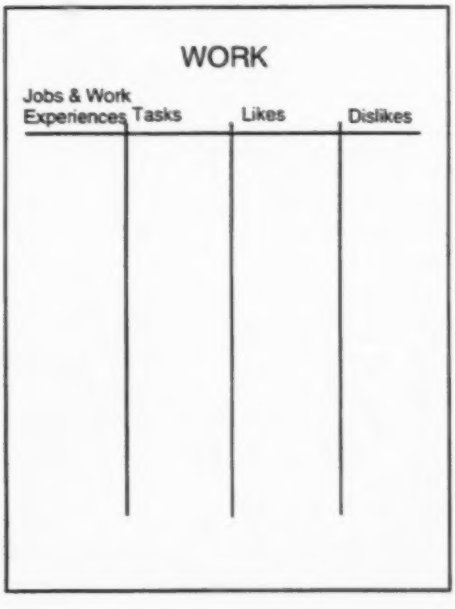

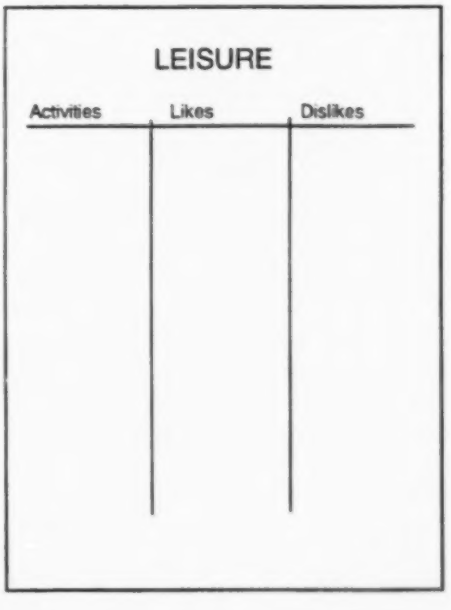

Sample Chartpaper Layouts: Format A
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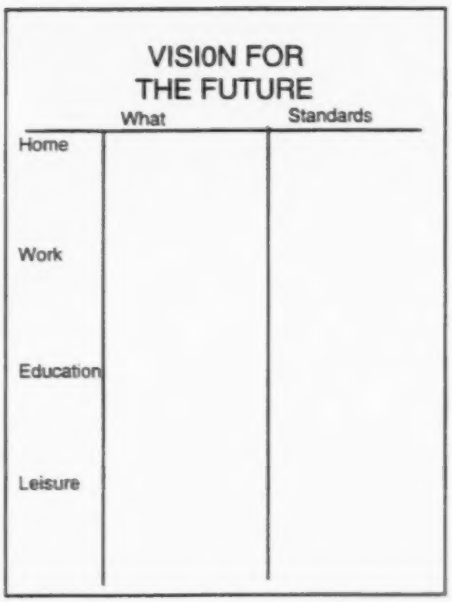
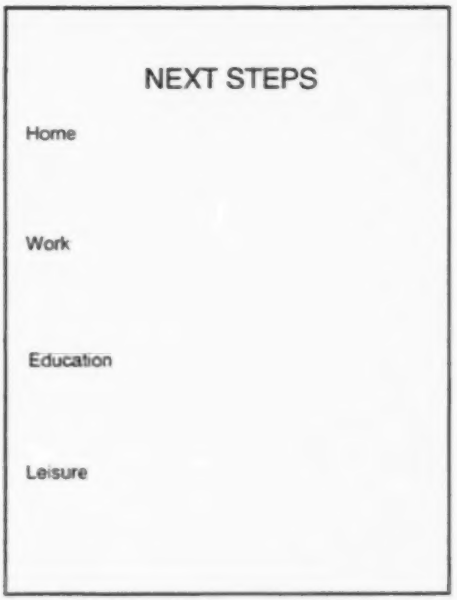
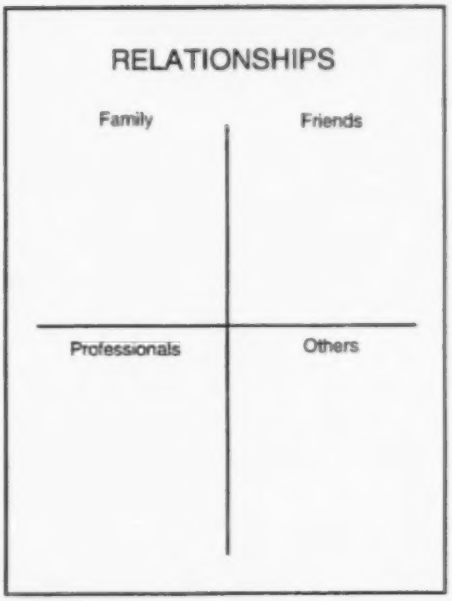
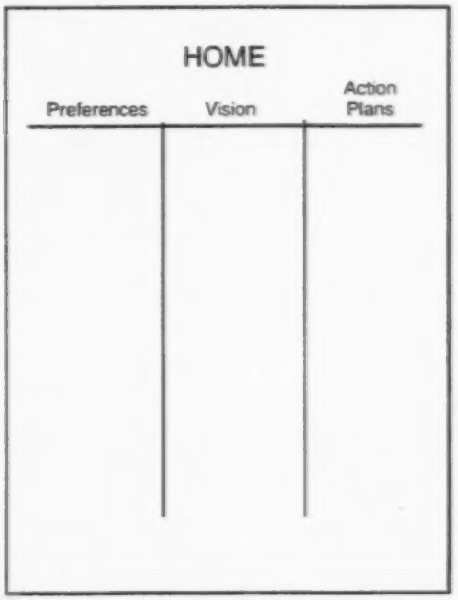
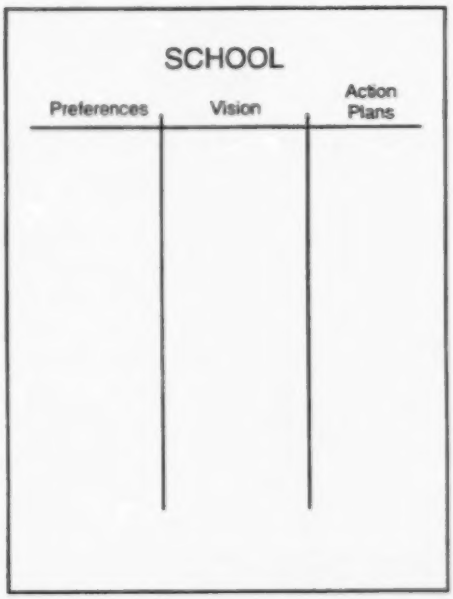


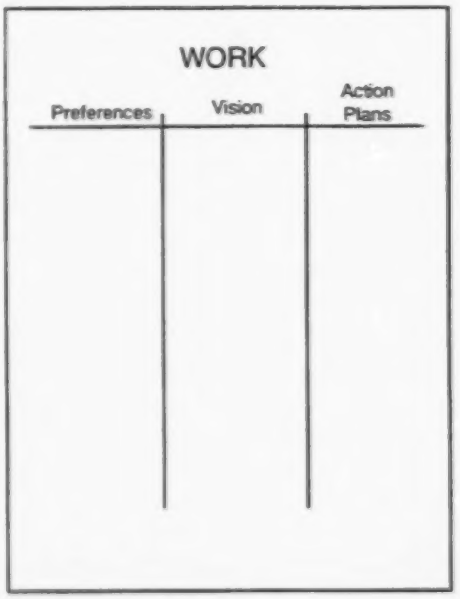


Sample Chartpaper Layouts: Format B









Sample Chartpaper Layouts: Format B
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